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Cancer Clusters

Defining Disease Clusters

A disease cluster is the occurrence of a greater than expected number of cases of a particular disease within a group of people, a geographic area, or a period of time. Clusters of various diseases have concerned scientists for centuries. Some recent disease clusters include the outbreak of Legionnaire's disease in the 1970s from contaminated water in air conditioning ducts, the initial cases of a rare type of [pneumonia](#) among homosexual men in the early 1980s that led to the identification of [human immunodeficiency virus](#)/acquired immune deficiency syndrome ([HIV/ AIDS](#)), and periodic outbreaks of food poisoning caused by eating food contaminated with bacteria.

[Cancer](#) clusters may be suspected when people report that several family members, friends, neighbors, or coworkers have been diagnosed with the same or related cancer(s). In the 1960s, one of the best known cancer clusters emerged, involving many cases of mesothelioma (a rare cancer of the lining of the chest and [abdomen](#)). Researchers traced the development of mesothelioma to exposure to a fibrous mineral called [asbestos](#). Working with asbestos, which was used heavily in shipbuilding during World War II and has also been used in manufacturing industrial and consumer products, is the major [risk factor](#) for mesothelioma.

Facts About Cancer

Some concepts about cancer can be helpful when trying to understand suspected cancer clusters:

- Cancer is the uncontrolled growth and spread of abnormal [cells](#) anywhere in the body. However, cancer is not just one disease; it is actually an umbrella term for at least 100 different but related diseases.
- Each type of cancer has certain known and/or suspected risk factors associated with it.
- Cancer is not caused by injuries, nor is it contagious. It cannot be passed from one person to another like a cold or the flu.

- Cancer is almost always caused by a combination of factors that interact in ways that are not yet fully understood.
- [Carcinogenesis](#) (the process by which normal cells are transformed into cancer cells) involves a series of changes within cells that usually occur over the course of many years. More than 10 years can go by between the beginning of carcinogenesis and the [diagnosis](#) of cancer. The long period of time between the first cellular abnormality and the [clinical](#) recognition that cancer is present often makes it difficult to pinpoint the cause of the cancer.
- Cancer is more likely to occur as people get older; because people are living longer, more cases of cancer can be expected in the future. This may create the impression that cancer is becoming much more common, when an increase in the number of cases of cancer is partly related to the aging of the population.

Almost 15 million new cases of cancer have been diagnosed since 1990. Therefore, it is not unusual for several cases of cancer to occur by chance or coincidence within the same family or neighborhood.

Facts About Cancer Clusters

Reported disease clusters of any kind, including suspected cancer clusters, are investigated by epidemiologists (scientists who study the frequency, distribution, determinants, and control of diseases in populations). Epidemiologists use their knowledge of diseases, environmental science, lifestyle factors, and biostatistics to try to determine whether a suspected cluster represents a true excess of cancer cases.

Epidemiologists have identified certain circumstances that may lead them to suspect a potential common source or mechanism of carcinogenesis among people thought to be part of a cancer cluster. A suspected cancer cluster is more likely to be a true cluster, rather than a coincidence, if it involves:

- A large number of cases of a specific type of cancer, rather than several different types;
- A rare type of cancer, rather than common types; or
- An increased number of cases of a certain type of cancer in an age group that is not usually affected by that type of cancer.

Before epidemiologists can accurately assess a suspected cancer cluster, they must determine whether the type of cancer involved is a primary cancer or a cancer that is the result of [metastasis](#) (spread from another organ). This is important because scientists consider only the primary cancer when they investigate a cancer cluster.

Epidemiologists also try to establish whether the suspected exposure has the potential to cause the reported cancer, based on what is known about that cancer's likely causes and what is known about the carcinogenic potential of the exposure. Scientists use various statistical methods to determine whether the reported excess of cases is really a larger number than would normally be expected to occur.

Before a cluster can be considered "true," epidemiologists must show that the number of cancer cases which have occurred is significantly greater than the number of cases that would be expected, given the age, gender, and racial distribution of the group of people at risk of developing the disease. However, it is often very difficult, if not impossible, to accurately define the group of people who should be considered "at risk." One of the greatest pitfalls of defining clusters is the tendency to extend the geographic borders of the cluster to include additional cases of the suspected disease as they are discovered. The tendency to define the borders of a cluster on the basis of where one knows the cases are located, rather than to first define the population and then determine if the number of cancers is excessive, creates many "clusters" that are not genuine.

For this and a variety of other reasons, most reported cancer clusters are not shown to be true clusters. Many reported clusters do not include enough cases for epidemiologists to arrive at any conclusions. Sometimes, even when a suspected cluster has enough cases for study, a true statistical excess cannot be demonstrated. Other times, epidemiologists find a true excess of cases, but they cannot find an explanation for it. For example, the suspected [carcinogen](#) may cause cancer only under certain circumstances, making its impact difficult to detect. Moreover, because people change residence from time to time, it can be difficult for epidemiologists to identify previous exposures and find the records that are needed to determine what kind of cancer a person had—or if it was cancer at all.

Heredity and Environment

Because most cancers are likely to be caused by a combination of factors related to heredity and environment (including behavior and lifestyle), studies of suspected cancer clusters usually focus on these two issues. However, establishing significant and valid evidence that a specific [genetic](#) factor leads to an increased chance that a specific environmental exposure will result in cancer (called a [gene](#)-environment interaction) requires studies of large populations over long periods of time. Researchers are just beginning to unravel the puzzle of carcinogenesis in terms of the roles of heredity and environmental exposures. Some of their discoveries are outlined below:

Heredity

- All cancers develop because of genetic alterations of one kind or

another. An alteration is a change or [mutation](#) in the physical structure of a gene that interferes with the gene's normal functions.

- Some alterations that increase the risk of cancer are present at birth in the genes of all cells in the body, including [reproductive cells](#). These alterations, which are called germline alterations, can be passed from parent to child. This is known as an inherited susceptibility. This type of alteration is uncommon as a cause of cancer.
- Most cancers are not due to an inherited susceptibility but result from genetic changes that occur during one's lifetime within the cells of a particular organ. These are called somatic alterations.
- Familial cancer clusters (multiple cases among relatives) have been reported for many types of cancer. Because cancer is a common disease, it is not unusual for several cases to occur within a family.
- Familial cancer clusters are sometimes linked to inherited susceptibility, but environmental factors and chance may also be involved.
- Having an inherited susceptibility for a type of cancer does not guarantee that the cancer will occur; it means there is an increased chance of developing cancer if other factors are present, or later develop, which promote the development of cancer.

Environment

- The term *environment* includes not only air, water, and soil, but also substances and conditions in the home and workplace. It also includes diet; the use of tobacco, alcohol, or drugs; exposure to chemicals; and exposure to sunlight and other forms of [radiation](#).
- People are exposed to a variety of environmental factors for varying lengths of time, and these factors interact in ways that are still not fully understood. Further, individuals have varying levels of susceptibility to these factors.
- Because workers may have heavier and more prolonged exposures to hazardous chemicals that are found widely distributed at lower levels in the general environment, positive findings from studies in the workplace provide important leads regarding causes of cancer in other settings. In fact, occupational studies have identified many specific chemical carcinogens and have provided direction for prevention activities to reduce or eliminate cancer-causing exposures in the workplace and elsewhere.

Reporting Suspected Cancer Clusters

Concerned individuals may report a suspected cancer cluster to their local health department. The local health department will refer the caller to the state health department, if necessary. Local and state health departments use established criteria in investigating reports of cancer clusters. Although health departments may use different processes, most follow a basic procedure in which increasingly specific information is obtained and analyzed in stages. Health departments are likely to request the following:

- Information about the potential cluster: type(s) of cancer, number of cases, suspected exposure(s), and suspected geographic area/time period.
- Information about each person with cancer in the potential cluster: name, address, telephone number, gender, race, age, occupation(s), and area(s) lived in/length of time.
- Information about each case of cancer: type of cancer, date of diagnosis, age at diagnosis, metastatic sites, and physician contact.

Most states currently have central registries that collect data on cancer [incidence](#) (the number of new cancer cases reported). The data in these registries can be used to compare expected cancer rates in certain categories, such as a geographic area, age, or racial group, with rates reported in a suspected cancer cluster to determine whether there is a true excess of cases.

When a suspected cancer cluster is first reported, the health department gathers information about the suspected cluster and gives the inquirer general information about cancer clusters. Between 75 and 80 percent of reports of suspected cancer clusters are resolved at this initial contact because concerned individuals realize that what seemed like a cancer cluster is not a true cluster.

If there is a need for further evaluation, the health department attempts to verify the reported diagnoses by contacting patients and relatives and obtaining medical records. It compares the number of cases in the suspected cancer cluster with information in census data and cancer ([tumor](#)) registries. It also reviews the scientific literature to establish whether the reported cancer(s) has been linked to the suspected exposure. State health departments often receive assistance from a number of federal agencies, including the Centers for Disease Control and Prevention, the Agency for [Toxic](#) Substances and Disease Registry, and the Environmental Protection Agency.

The health department may gather additional information to help decide whether to conduct a comprehensive epidemiological study. Most state health departments report that fewer than 5 percent of cancer cluster investigations reach the final stage of actually conducting the comprehensive study.

Resources

Local and state health departments are listed under such headings as "health department" and "public health commission" in the Blue Pages of Government Listings in telephone books. Information about cancer clusters is also available from other sources.

The NCI's Cancer Mortality Maps & Graphs Web site provides interactive maps, graphs, text, tables, and figures showing geographic patterns and time trends of cancer death rates for the time period 1950–1994 for more than 40 cancers. It also provides interactive mortality charts and graphs, customizable mortality maps, and links to related domestic and international Web sites, including a link to the online publication of NCI's *Atlas of Cancer Mortality in the United States: 1950–94*. The NCI's Cancer Mortality Maps & Graphs Web site can be accessed at <http://cancer.gov/atlasplus/> on the Internet.

General information about environment-related diseases and health risks is available from the National Institute of Environmental Health Sciences (NIEHS). The address for the NIEHS is Room B1C02, Building 31, 31 Center Drive MSC 2256, Bethesda, MD 20892. The NIEHS Web site is located at <http://www.niehs.nih.gov> on the Internet.

Callers to local and state health departments who report suspected cancer clusters that occur in occupational settings may be referred to the National Institute for Occupational Safety and Health (NIOSH). Through its Health Hazard Evaluation (HHE) Program, NIOSH investigates potentially hazardous working conditions, including suspected cancer clusters, when employers, authorized employee representatives, or employees request it. More information about the HHE Program is available by calling (toll-free) 1–800–356–4674 (1–800–35–NIOSH). The telephone number for callers living outside the United States is 513–533–8328. The mailing address for the HHE Program is: Hazard Evaluations and Technical Assistance Branch, NIOSH, Mail Stop R-9, 4676 Columbia Parkway, Cincinnati, OH 45226. The NIOSH Web site is located at <http://www.cdc.gov/niosh/homepage.html> on the Internet.

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Sources of National Cancer Institute Information

Cancer Information Service

Toll-free: 1–800–4–CANCER (1–800–422–6237)

TTY (for deaf and hard of hearing callers): 1–800–332–8615

NCI Online

Internet

Use <http://cancer.gov> to reach NCI's Web site.

CancerMail Service

To obtain a contents list, send e-mail to cancermail@cips.nci.nih.gov with the word "help" in the body of the message.

CancerFax® fax on demand service

Dial 1-800-624-2511 or 301-402-5874 and follow the voice-prompt instructions.